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Electronic Newsletter
March 2010

Message from the Chairman:

As we approach Autism Awareness Day – a key event in the observance of Autism Awareness Month each April – I am filled with a mixture of excitement and apprehension. On the one hand, we have made enormous strides in bringing the concerns of our families to the attention of our legislators and other officials. Our insurance bill, ARICA, is moving through the legislative process; other AFAM legislative priorities, including the anti-bullying bill and the augmentative and alternative communication bill, are also moving along; and our report on the state of Adult Services is due to be released in the next few weeks. On the other hand, continuing economic woes raise the threat of additional budget cuts to family support, day and employment services, and other funding for services our families depend upon.

In this context, It is important for our families to continue to advocate on behalf of their loved one impacted by an autism spectrum disorder. Autism Awareness Day, which will be held at the State house on April 13, is an ideal opportunity for you to reach out to your own representatives in the Massachusetts legislature.

I urge you to make appointments with your legislators in advance to discuss the importance our community's priorities. Your AFAM representatives will work diligently to advocate on behalf of you and other families impacted by an autism spectrum disorder, but we cannot do it alone. We need your active participation!

I hope to see you on April 13th. I continue to urge you, your family and friends to join us and participate in this process so our voice may be heard!

Michael J. Borr, Chairman
AFAM Executive Committee

Government Affairs Committee

This past week there were some positive developments regarding AFAM's legislative priorities:

H. 3804, An Act Addressing Bullying of Children with ASD

This bill amends the Autism IEP Act to clarify that IEP teams must address bullying of children with ASD. A hearing before the Joint Committee on Education was held on October 20, 2009. On February 23, 2010, the Education Committee voted out favorably a consolidated bullying bill which incorporated H. 3804 into the larger bill. If passed, it will mandate that children with ASD receive training in how to avoid and respond to bullying. It will now go before the Senate for consideration.

S. 223, An Act to Improve Augmentative and Alternative Communication Opportunities for Children with Disabilities

This bill will help ensure that teachers receive training in AAC methods necessary to educate children with disabilities who are nonverbal or have limited speech. A hearing before the Joint Committee on Education was held on October 20, 2009. It was also voted out favorably on February 23, 2010 and will now go to the Senate for consideration.

AFAM will continue to keep you apprised of legislative developments and reach out and ask for your assistance in garnering support to help gain passage of these important pieces of legislation in the coming months. We look forward to seeing everyone at Autism Awareness Day.

Ann Guay, Chair
Government Affairs Committee

Insurance Policy Committee

ARICA is being analyzed by the State's Division of Health Care Policy and Finance, as per legislative requirements for all mandates. We are awaiting the results of this analysis (early Spring), and remain optimistic that the bill will be ruled on favorably by the Committee and move swiftly after this point. We will be in touch in the interim if there are news updates or if we need direct response from all of you. In the meantime, please continue to remind your legislators that medical insurance for autism treatment is of critical importance to you and your family.

Amy Weinstock, Chair
Insurance Policy Committee.

Adult Services Committee

AFAM Releases Adult Services Report: Awash in Autism - Why We Must Begin to Address the Critical Need for Services for Adults with Autism in Massachusetts

Massachusetts is facing a crisis. An entire generation of school children with Autism Spectrum Disorders (ASDs) is becoming adults. The tsunami is now on the horizon. **Indeed the beginning of the wave is hitting the classes of individuals currently Turning 22.** The supports necessary to enable these young adults with ASD to live fulfilling lives, safe from harm and crisis, just do not exist in forms or to extents adequate to their intense needs or their growing numbers.

This month AFAM is releasing a report prepared by its Adult Services Committee: **Awash in Autism - Why We Must Begin to Address the Critical Need for Services for Adults with Autism in Massachusetts.** The report includes an overview of the current state of services in Massachusetts for adults with ASDs prepared for AFAM by Caroline V. Budney, M.P.P., and Marji Erickson Warfield, Ph.D., of the Lurie Institute for Disability Policy, Heller School for Social Policy and Management, Brandeis University. The report also summarizes the findings of needs survey that AFAM conducted over the past year documenting the needs of individuals in Massachusetts 14 years and older who have or will have needs for intensive and specialized day, employment, and residential supports when they reach the age of 22. **Over 260 families participated in our survey and we thank them for their time and input.**

In the report, AFAM calls on the Commonwealth to establish **a task force** to begin the work necessary to develop a more complete understanding of the current status and future needs of adults with autism in Massachusetts and assist in the development of effective policy and service options. We recognize that services for people with disabilities in the Commonwealth are severely underfunded and overwhelmed, and we are in the throes of a great fiscal crisis. **But the challenge before us needs to be addressed: the numbers of adults with autism who are now reaching adulthood and the intensity and nature of their needs make this an imperative that cannot be ignored or delayed.**

Each legislator in the Massachusetts House of Representatives and Senate will receive a copy of the report as will other policy makers in the State administration and in the disability community. **Check out the Adult Services page of the AFAM website to view a copy of the report and a complete summary of the survey results.**

Christine Hubbard, Chair
Adult Services Committee

Autism Awareness Day at the State House: Tuesday, April 13. With the economy still in bad shape, legislators are once again taking a hard look at budgets. That means it's more important than ever to participate in the annual ASD Awareness Day at the State House in Boston, to lobby your state representatives and state senators about the need for enhanced services for individuals on the spectrum. Please plan to join us in the Great Hall of the State House on Tuesday, April 13, beginning at 9:00 a.m. This year's theme is "Awash in Autism: Ask Me About 1 in 110," a reference to the most recent CDC figures on the incidence of ASD. The program includes presentations on the work of AFAM's Government Affairs, Insurance, and Adult Services committees, updates from government officials, and awards to those who have made significant contributions to the ASD community. AFAM will provide you with up-to-date "talking points," so you can speak knowledgeably about pending legislation and budget priorities when you visit your own legislators. Please encourage your friends and family members, too – all our voices are important! And bring photos of your family member, so our elected officials can see that autism isn't just about numbers, it's about people!

Wine Sale Extended – it's now year-round! Looking for a way to celebrate a birthday, holiday, anniversary, graduation or other special occasion? You can now order AFAM private-label wines year-round (and not just at holiday time) by visiting our website, www.afamaction.org. Your purchases help support AFAM's ongoing advocacy on behalf of people with ASD and their families across Massachusetts.

Photos wanted for the AFAM Website. Do you have photos of your child or adult family member with ASD that you'd be willing to share with those who visit AFAM's website? If so, please send them (in jpeg format) to our webmaster at Jeanne@jeannewilliamson.com. Please put "for AFAM website" in the subject line.

How Can You Help? People often ask us how they can support AFAM's work. The most important way, of course, is to let your legislators on Beacon Hill know about the needs of families who face the challenge of caring for the needs of children and adults with ASD. Let them know about AFAM's legislative and budget priorities, and participate in events such as Autism Awareness Day. Let them hear from you by phone, mail or email when you receive AFAM's legislative alerts.

Another way is by providing financial support for AFAM's work. Since we no longer collect annual dues, all donations to AFAM are voluntary. You may even want to consider making a contribution in honor of someone (on their birthday or anniversary or in celebration of a milestone in someone's life) or by memorializing someone who has passed away. Whatever you choose to do, be assured that your donation will be gratefully received and will be put to good use.

News and Announcements

Save the Dates for 2 great AFAM events!

The first one – **The Jazz Masters with Karrin Allyson and Jay Geils** -- will take place on **Friday, May 14** at the **Showcase Live Theater at Patriot Place in Foxborough**. Doors will open at 6 p.m. for dinner and best seat selection; show time is at 8 p.m. Tickets for the show are \$25 per person (dinner is not included) and will be available from AFAM beginning on March 8. This show is expected to be sold out very quickly, so send in your reservations early. Mail your check (payable to The Arc of Mass./AFAM) to AFAM, 217 South Street, Waltham, MA 02453.

Then, for your summer pleasure, on **Sunday, August 8** AFAM has planned a fabulous club date at the **C-Note at Nantasket Beach (Hull)**, from 2 to 9 p.m., with a terrific group of bands. Thanks to the generosity of the bands and club owner, Charlie Fruzzetti, this event will raise funds to support AFAM's ongoing advocacy. More details later, but be sure to mark your calendars and plan to join us.

The Autism Support Center has a new website (www.ne-arc.org) and a new email address: asc@ne-arc.org

AANE invites parents of children and teens to attend a workshop, **Financial Planning for the Future of Your Child with Special Needs** on Wednesday, March 3 from 7:30 to 9:30 p.m. at the AANE office (85 Main Street, Suite 101, Watertown). Presenters are Dave Harmon, MBA, CLU, ChFC and Special Needs Attorney Ken Shulman. Cost is \$10 per person for AANE members and \$25 per person for non-members. Space is limited, and advance registration is required. You must register online at www.aane.org

The **15th Annual ASD Symposium**, co-hosted by Dr. Barry Prizant and **Community Autism Resources**, will take place on March 11-12 at the Rhodes on the Pawtuxet (60 Rhodes Place, Cranston, RI). On Thursday, March 11 you can spend the morning with Temple Grandin and the afternoon with Elaine Hall of "Autism: The Musical." On Friday, March 12, spend the day with Dr. Pat Miranda, whose program is "Beyond Wants and Needs: Using AAC to Support Social Interactions." You can register online at www.community-autism-resources.com or call Kelly at 508-965-5705.

The Autism Support Center presents a program on **Social Security Benefits and Employment for Young People with Disabilities** with presenter Brian Forsy on Thursday, March 11 from 10 am to 12:00 PM at the Chelmsford Public Library, McCarthy Meeting Room - kitchenette side. This presentation will address: SSI and SSDI in the transition to the age of adulthood (18) and the age of leaving the special education system (22) ; Social Security's childhood disabilities benefits for parents of younger children who may have a need based

on the medical support requirements of their child; Provide a general overview and answer questions. .RSVP to wenlima@msn.com

Asperger's Association of New England, in partnership with MGH Youth Care, presents **Asperger Syndrome and Anxiety: Perspectives and Intervention** on Friday and Saturday, March 26-27 at MIT in Cambridge. The program, which offers Continuing Education Credits, is designed for social workers, psychologists, therapists, school counselors and other professionals, as well as parents and adults with Asperger Syndrome. Space is limited, so make your reservation early. For further information, contact AANE (617-393-3824) or visit their website (www.aane.org).

Melmark New England will offer a program on **Before/After Transition** on Monday, April 5 from 7:00 to 8:30 p.m. at Melmark New England (461 River Road, Andover). Presenters are Frank L. Bird and Lisa Struder. To register, contact Karen Fitzgerald at 978-654-4351 or kfitzgerald@melmarkne.org

Community Resources for People with Autism will hold its **20th Annual Conference** on Tuesday, April 6 at the Log Cabin Banquet and Meetinghouse (500 Easthampton Road, Holyoke). Speakers include Brenda Smith Myles, Ph.D. and Valerie Paradiz, Ph.D. Registration begins at 8:00 a.m.; the program runs from 9:00 a.m. to 3:30 p.m. and includes lunch. Registration and payment must be received by April 1. You can download a registration for by visiting their website, www.communityresourcesforautism.org For further information contact Karen Greaney (phone 413-529-2428, ext. 118; email greaneyk@theassn.org).

The Doug Flutie, Jr. Foundation for Autism and **Children Making Strides** will hold its 10th Annual **Autism Update Conference** on Thursday, April 8 at the Sheraton Four Points in Norwood. The Keynote Address will be given by Tim Buie, MD with the Lurie Family Autism Center presenting an overview of his newly published research on digestive problems in children with autism. Other topics include "The State of Autism Services in Massachusetts," with Dr. Jean McGuire, Facing the Future for Adults With Autism - a panel discussion, Today's Technology for People with ASD and Supporting Students With Challenging Behaviors. For more information, visit the Foundation's website: www.flutiefoundation.org

Community Autism Resources will hold **Rockin' the Night Away**, a night of music and dancing to benefit CAR on Saturday, April 10 from 8:00 p.m. to midnight at The Shaw's Center in Brockton. The program includes live music, dancing, food, raffles and much more! For tickets and more information, contact Lisa Oliviere at 508-272-0761.

The Doug Flutie, Jr. Foundation presents **Doug Flutie Celebrity Rock 'N Hoops** on April 16 at the Basketball Hall of Fame, Springfield, MA. Come watch Doug Flutie and local celebrities play basketball versus the Court Jesters comedy

basketball group at the Basketball Hall of Fame in Springfield, MA, the birthplace of basketball. After the game you will be entertained by the Flutie Band - a fun night for the whole family! Cost: Tickets are \$50 each and include admission to the basketball game, the post game concert & admission to the Basketball Hall of Fame. All tickets are general admission. For tickets, sponsorship or more information please contact Kerri Blume at the Flutie Foundation at 508-270-8855 or kerri@flutiefoundation.org

The Autism Support Center will hold a **Bike Clinic** on Thursday, April 22 from 11 a.m. to 1 p.m. at the Proctor School, 60 Main Street, Topsfield. Is your son or daughter having difficulty learning to ride a bike? This hands-on clinic is for children on the autism spectrum and their siblings ages 5 and up. Skilled volunteers will be available to work with participants on the fun, healthy, activity. Bring your own bike and helmet. For registration information, contact Scott Buchanan at 978-624-2347 or sbuchanan@ne-arc.org

The Autism Alliance of Metrowest, a program of Advocates, Inc. and **The Doug Flutie, Jr. Foundation for Autism, Inc.** will hold their **10th Annual Kite Day** at Bose Mountain (Mountain Road, Framingham) on Sunday, April 25 from Noon to 4:00 p.m. Join in celebrating Autism Awareness Month with free kites, face painting, musical activities, bottled water and much more. You can fly your own kite, buy a kite, or fly one of the gift kites. It's a great family fund day with something for everyone. Rain date is May 2. For more information, contact the Autism Alliance of Metrowest at 508-652-9900 or visit their website: www.autismalliance.org

Save the Date for **AANE's Annual "Evening of Laughs" Gala** on Saturday, May 1 at the Newton Marriott Hotel. This gala event will be hosted by Mike O'Malley and will feature comedian Bob Marley. For further information visit the Asperger's Association website (www.aane.org) or contact kelly.genois@aane.org

The Lurie Family Autism LADDERS program announces the 3rd Annual: Roger A. Bauman M.D. Parent Lecture Series for 2010. Schedule and speakers are as follows:

March 24: Physician Panel (Drs. Margaret Bauman, Patty Davis, Susan Connors, Tim Yu, Kathy Martien, Ann Neumeyer and others) who will discuss their current clinical and research interests and projects); Lurie Family Autism Center, LADDERS of Mass General Hospital For Children

April 28: "Social Competence and Social Skills Groups for Children with Autism Spectrum Disorders", expert panel: Dr. Al Cotugno, MGH/Youthcare and Lori Hodgins Brazell, Adventures Outside The Box

May 19: Susan Senator, Mother of child with ASD; author of "Making Peace with Autism" and the "The Autism Mom's Survival Guide"

June 16: To be announced

When: *All programs are on Wednesday evenings from 6:30 p.m. to 8:30 p.m.*

Where: *Charles River Center, 59 E. Militia Heights Rd, Needham, MA (located at the top of Dwight Rd, off of Central Street) in the Paul D. Merritt Center* For directions, please visit www.crarc.org

YOU MUST RSVP/REGISTER please contact Julie O'Brien, Resource Specialist, Autism Consortium, LFAC/ LADDERS at 781-860-1726, jobrien20@partners.org *For updates on the schedule visit: www.ladders.org and www.autismconsortium.org events page **LIMITED CHILDCARE MAY BE AVAILABLE BY PRE-REGISTRATION ONLY AND IN ADVANCE**, contact Julie O'Brien at 781-860-1726

TASH New England will hold its 2010 Conference on Friday, April 9 at the Hogan Campus Center of the College of the Holy Cross in Worcester. The keynote address, "Advocacy for All: A View from Within," will be given by Stephen Shore, Ed.D., who is President Emeritus of the Asperger's Association of New England. For further information, visit the TASH website: www.tash.org

Milton Parks and Recreation Presents: "Lose the Training Wheels" Program, from April 19-23 (School Vacation Week), for children at least 8 years old and older. The objective of Lose the Training Wheels is to teach individuals with disabilities to ride a conventional two wheel bicycle without training wheels. The program uses specialized equipment, coaching and encouragement to reach this goal. Through the use of our equipment, we gradually introduce the instability of the bicycle until the participant "discovers" how to ride a bike.

Participants will attend one session (75 minutes) per day for a total of five days. During the session each participant will ride indoors on an adapted trainer bike and a conventional bike once they have achieved that skill level. Participants are required to wear a properly fitting helmet when they are on a bike.

For complete information regarding this program for your child OR to volunteer please contact: Dave Perdios (617) 898-4941 or dperdios@townofmilton.org

The Flutie Foundation is partnering with AccesSportAmerica to bring summer fun in its 2010 Water Sports Program. Sessions will be held at the Mass. Hospital School in Canton and, back by popular demand, a couple of Saturday sessions will be offered at Spaulding Rehab in Boston. Visit their website (www.flutiefoundation.org) for more information and to download the registration form. Registration will be done on a first come, first served basis and will fill up very quickly!

Bailey's Team is sponsoring an education series to be held at the Holiday Inn Mansfield-Foxboro. The following sessions have been scheduled, all on Wednesday evenings: April 14: "What it's Like to be Autistic," presented by Stephen Shore, Ed.D.; May 12: "Finding Balance Living with Autism: Family Experiences and Coping Strategies," presented by Barry Prizant, Ph.D.; and June 16: "Autism in the Community: Inclusion and Acceptance," presented by

Susan Constable, M.Ed. and Janet McTarnaghan, M.Ed. Registration is at 6:30 p.m. and presentations begin promptly at 7:00 p.m. For information, visit their website: www.baileysteam.org or contact Sammi Robertson (sammirobertson@comcast.net)

Because of budget cuts and internal restructuring, **Community Resources for People with Autism** is seeking **Parent-to-Parent Volunteers** who can share experiences and insights with other families in need of support. They are compiling a list of local parents of children with ASD who have been involved with Community Resources in the past and have demonstrated a strong knowledge of autism as well as local resources. Contact information will not be made public but will be offered to parents who are specifically seeking a connection with a local parent. If you are interested in being a Parent-To-Parent Volunteer, contact Beth Crosby at Community Resources (413-529-2428, ext. 115 or crosbye@theassn.org)

Dr. Wendy Coster of Boston University is looking for parents of children with ASD to participate in an online focus group forum on **Adaptive Behavior of Children and Youth with Autism Spectrum Disorders**. The project is looking at whether a newly developed survey measure is appropriate to capture the achievements and challenges of children and youth with ASD as they develop the skills of daily life. They are looking for parents and clinicians to review the instructions, items and rating scales the researchers have developed and give them feedback about those items. Participants will receive a \$20 gift certificate at the conclusion of the program. For more information, visit their website (www.bu.edu/kidsincontext) or contact Assistant Prof. Jessica Kramer at 617-353-2702; email kramerj@bu.edu

The Institute on Disability, University of New Hampshire will hold its **12th Annual Autism Summer Institute** at the Crowne Plaza Hotel in Nashua, NH from August 9-12. This year's theme is "A New View of Students with ASD: Implications for Inclusive Education." Registration information will be available in March. For information, contact the Institute (603-862-4320).

For additional announcements, please visit the websites of our Founding Organizations

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